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## CPD LEGACY STORY: RENA VANZO

September 22, 2010 by cpehrson

This CPD Legacy Story is from Rena Vanzo, MS, LCGC. Rena was a student in the 2009-2010 Utah Regional Leadership Education in Neurodevelopmental Disabilities Program-Autism Spectrum Disorders (URLEND/ASD) program.

The URLEND program is a multi-state collaborative CPD program that provides training to advanced standing trainees in health care and prepares them to become leaders in the Maternal and Child Health Care field. The URLEND/ASD program offers additional training in the area of autism.



Rena Vanzo

My name is Rena Vanzo and I am a genetic counselor who works at the University of Utah in the Department of Pediatrics. Genetic counseling is a communication process which deals with the problems associated with the occurrence, or risk of occurrence, of a genetic condition in a family. This process involves helping the individual and family to understand the medical facts, the course of the condition, and the treatment/management options; to understand what other relatives may be at risk; and to make the best possible adjustment and most informed choices regarding the diagnosis. Specifically, I work in the Metabolic Clinic, where we care for children with diagnoses from newborn screening and also in the Pediatric Genetics Clinic, where individuals with medical and/or developmental problems are assessed for the possibility of a genetic condition.

I decided to apply for the URLEND program this year (2009-2010) to familiarize myself with local resources that could best serve my patients and their families. I was certainly able to accomplish that goal. For example, during the training, I learned about a local social skills group for teens with autism or autistic spectrum disorders, the Craniofacial Clinic and its various multidisciplinary providers, and the Newborn Followup Program for premature infants, to name a few. I plan to offer these resources to the families I work with that would benefit from them. I also know, now, what to tell those families to look forward to and expect if they go to these programs.

While this was my main goal in taking the URLEND training, I had no idea about all of the other valuable experiences that were in store for me.

After completing a year of URLEND, I have no doubt improved in my abilities as a genetic counselor. Throughout the year I was introduced to many tools that can improve patient satisfaction, and ideally patient quality of life. For instance, one clinic uses a patient questionnaire to address sensitive topics like insurance coverage and depression for parents, and teasing/bullying for teenagers. I plan to use these questionnaires to help bridge the gap from avoiding these topics to bringing them into the light so families can get assistance, as needed.

I also became aware of very important issues that exist in our healthcare system, such as disparities for those with disabilities, which need to be recognized and corrected. Additionally, ideas such as person-first language and family-centered care while appreciating patient individuality and autonomy were focus points, which reinforces themes that underlie the principles of genetic counseling.

Another important activity that came through URLEND was providing a presentation on Genetics and Prenatal Care at the South Main Clinic, which primarily serves Spanish-speaking families. This presentation really turned into a discussion with about 10-12 women who have children with a genetic condition. This gave me a unique, invaluable opportunity to learn what information my patients seek most during their appointments with a genetics professional, and, perhaps most importantly, the areas and topics about which they need to be reassured.

I was also involved in the Autism Enhancement portion of URLEND, which allowed me to become comfortable and knowledgeable discussing the complexities of autism and answering parent's questions. I was also personally able to educate my fellow URLEND trainees on a rare cause of autism. My goal has been to spread the word about this particular cause of autism (called cerebral creatine deficiency syndromes)

as patients are followed, managed, and to a large extent, treated in the Metabolic Clinic. I am currently working on a publication with the hopes of spreading awareness for this treatable condition. All in all, I am more confident to capable of taking on tasks (such as publication!) that were unbelievably intimidating before my experience with URLEND.

These are just a few of the varied and incredible experiences that I have gained over the past year in URLEND. It is a fantastic multidisciplinary program, and I would recommend this to any healthcare professional who works with children and families with disabilities, whether that professional is new or practiced in their career.